

NAVIGATING MYELODYSPLASTIC SYNDROMES (MDS)

The Journey Informed: A Patient-Focused Roadmap to Managing MDS

This is a navigation tool designed for patients with **MDS**, their care partners, and the multidisciplinary team to:

- Provide patients and care partners with valuable education to use throughout their care journey
- Equip the care team with a tool to assist in maneuvering patient conversations
- Highlight key milestones and evidence-based considerations of the MDS care journey

📖 = Key Terms found on the back side of this resource.

BEGIN

1

Leading up to my diagnosis with MDS¹:

Several tests should have been performed to help determine my **risk status** (eg, low- or high-risk), including:

- Bone marrow aspiration, biopsy, and **cytogenetic testing** 📖
- **Genomic testing** 📖

Patient Takeaways:

- I should receive education on my **risk status**, which helps to determine my treatment options
- **Risk status** also informs my risk for transformation to acute myeloid leukemia (AML)

Navigator Role:

- Provide diagnosis-specific education and resources (including risk status, disease outlook, etc)
- Encourage shared decision-making

2

Throughout my care journey with MDS¹⁻³:

- I will need periodic **laboratory testing** (*blood draws*) to check my blood levels and assess for any needs I may have (including **blood transfusions** and/or other supportive care measures)
- I may receive medication for **treatment**. I may be a candidate for **allogeneic stem cell transplantation (allo-SCT)** 📖, and/or I may be eligible for a clinical trial
- I should report any **needs** or **barriers to care** to my healthcare team throughout my entire journey

Patient Takeaways:

- I should ask my care team if there is an open **clinical trial** nearby
- Goals of my **treatment** are to control the natural progression of my MDS or to improve my quality of life by restoring my blood counts to normal levels and minimizing my need for transfusions

Navigator Role:

- Provide treatment-specific education and resources
- Regularly assess for any needs or barriers to care
- Support multidisciplinary coordination of care
- Facilitate appropriate referrals to supportive services (eg, advocacy groups, financial navigation, **palliative care** 📖, patient navigation, psychosocial support)

3

As management of my MDS^{2,3}:

- I may need more than one course of treatment due to nonresponse, disease progression, or other reasons
- I will have frequent **follow-up appointments** to assess for any needs I may have, my response to treatment, and my prognosis based on results from my **lab tests**

Patient Takeaways:

- Frequency of **lab tests**, **blood transfusions**, and **follow-ups** with healthcare providers may be highly dependent on factors specific to me (eg, age, overall health status, etc)

Navigator Role:

- Educate on important side effects to check for and when to report to the care team
- Regularly assess for side effects and any needs or barriers to care
- Promote side effect management measures to minimize impacts

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KEY TERMS

- **Allo-SCT** is the process of destroying cells in the bone marrow using [chemotherapy or radiation] and replacing them with healthy, blood-forming cells from another person through a transfusion or a slow infusion of blood through a vein⁴
- **Cytogenetic testing** is the examination of whole chromosomes in individual cells under a microscope to look for any abnormal differences⁵
- **Genomic testing** is the detailed examination of the complete set of genes or genetic information to look for any genetic changes⁵
- **Palliative care** is given to patients at any stage of a serious illness and along with curative treatment to provide symptom relief and psychosocial support, which aims to improve quality of life (QOL) for both patients and care partners⁶
- **Hospice care** focuses on symptom management and QOL care for people with an anticipated life expectancy of 6 months or less⁷

Along my journey with MDS^{1,3}:

- My care team could change throughout my journey depending on my treatment plan
- My treatment outcomes may include a period of remission (**no detectable disease**), relapse (disease recurrence), or I may become a long-term survivor

Patient Takeaway:

- Prolonged **disease-free** survival has been reported in ~30% to 50% of patients receiving **allo-SCT**⁴, a potential curative treatment option for MDS¹

Navigator Role:

- Coordinate follow-ups and support multidisciplinary coordination of care
- Ensure appropriate disease monitoring is performed
- Educate on late and long-term side effects, signs & symptoms of recurrence and/or disease progression, and when to report to the care team
- Incorporate QOL goals into survivorship care plans

For more information, scan here using the camera of your mobile device/cell phone:



REFERENCES

1. Garcia-Manero G, Chien KS, Montalban-Bravo G. Myelodysplastic syndromes: 2021 update on diagnosis, risk stratification and management. *Am J Hematol*. 2020;95(11):1399-1420.
2. Fenaux P, Platzbecker U, Ades L. How we manage adults with myelodysplastic syndrome. *Br J Haematol*. 2020;189(6):1016-1027.
3. Platzbecker U, Kubasch AS, Homer-Bouthiette C, Prebet T. Current challenges and unmet medical needs in myelodysplastic syndromes. *Leukemia*. 2021;35(8):2182-2198.
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6. What is palliative care? Center to Advance Palliative Care. <https://getpalliativecare.org/whatis/>. Accessed Oct. 24, 2023.
7. What is hospice? Hospice Foundation of America. <https://hospicefoundation.org/Hospice-Care/Hospice-Services>. Accessed Oct. 24, 2023.

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My journey with MDS may transform into AML²:

- **AML** is a form of blood cancer that can arise from MDS
- Active treatment may not always be an option. In this case, I should begin to consider what is most important to me as I approach the last stages of my life

Patient Takeaways:

- Ask my care team about my risk for AML and what I need to know
- Ask my care team about symptom management and **hospice care**⁷

Navigator Role:

- Provide resources, education, and any needed support
- Discuss goals of care and advance care planning
- Facilitate appropriate referrals to supportive services (eg, advocacy groups, financial navigation, **hospice care**⁷, psychosocial support, etc)

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This resource was developed in collaboration with Gilead Sciences, Inc.

Navigating Myelodysplastic Syndromes (MDS)

The Basics of MDS and Helpful Information Guiding Your Journey

What are MDS?^{1,2}

- ▶ MDS are a diverse group of bone marrow disorders, where the body no longer makes enough blood cells in the bone marrow
- ▶ MDS are considered a form of blood cancer and are associated with a risk for disease transformation to a form of blood cancer called acute myeloid leukemia (AML)

How common are MDS?¹

- ▶ MDS occur in 3-4 people per 100,000 in the United States
- ▶ MDS are more common in men and in people aged 60 years or older

What typically leads to detection of MDS?¹

- ▶ MDS are often suspected by presence of a cytopenia on a routine blood test
 - Presence of a cytopenia means that you have a lower-than-normal number of blood cells

What signs and symptoms are common with MDS?³

- ▶ Signs and symptoms of MDS are typically related to cytopenias and include:
 - Fatigue
 - Easy bruising and/or bleeding
 - Increased risk of infections

What do patients with MDS typically experience?²

- ▶ Patients with MDS experience:
 - Ineffective regulation of the blood cell production process
 - Variable cytopenias
 - Risk of disease transformation to AML

What factors are considered for risk status?³

- ▶ Risk status takes into account several factors, including:
 - Number or degree of cytopenias
 - Cytogenetic profile
 - Percentage of bone marrow blasts (% Blasts)
- ▶ There are several different scoring systems used to establish the risk status of patients with MDS

Talk to your healthcare provider about the scoring system used to determine your risk status, as well as the different factors accounted for.

Why is knowing my risk status important?¹

- ▶ Risk status is important because it may impact the treatment and management of my MDS, as well as my risk for disease transformation to AML
 - Risk status may also determine my eligibility for clinical trials

What factors may contribute to making a treatment decision?¹

- ▶ Several factors contribute to treatment decisions, including, but not limited to, my:
 - Risk status
 - Need for blood transfusions
 - Cytopenias (frequency and severity)
 - Age
 - Candidacy for allogeneic stem cell transplant
 - Other health conditions (type and severity)
 - Quality of life
 - Life milestones

What is the relevance of AML?¹

- ▶ MDS have a risk of transforming to AML, another form of blood cancer

Risk for transformation should be considered at the time of diagnosis with MDS, as MDS disease characteristics ultimately impact risk for transformation to AML.



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Academy of Oncology
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Potential members of my care team

- Financial navigators
- Financial counselors
- Nurses
- Nurse navigators
- Pharmacists
- Nurse practitioners and/or physician assistants
- Dietitians
- Spiritual care providers
- Social workers
- Patient navigators
- Palliative care and/or hospice care providers
- Physicians (hematologists and oncologists)
- Rehabilitation (physical and occupational therapy)

Support and/or advocacy groups⁴⁻¹⁰

- The MDS Foundation:
www.mds-foundation.org
- The MDS Alliance:
www.mds-alliance.org
- Leukemia & Lymphoma Society:
www.lls.org
- The Aplastic Anemia and MDS International Foundation: www.aamds.org
- American Cancer Society (ACS):
www.cancer.org
- Patient Advocate Foundation:
www.patientadvocate.org
- PAN Foundation:
www.panfoundation.org

Resources¹¹⁻¹⁵

- Be the Match:
www.bethematch.org
- National Bone Marrow Transplant Link:
www.nbmtlink.org
- Cleaning for a Reason – Home Cleaning:
www.cleaningforareason.org
- Blood & Marrow Transplant Information Network:
www.bmtinfonet.org
- ACS Road to Recovery – Transportation for Treatment:
www.cancer.org/support-programs-and-services/road-to-recovery.html

Resources may include referrals to independent third-party nonprofit patient assistance programs. These programs are not operated or controlled by Gilead, and Gilead does not endorse any program or third-party organization.

References

1. Garcia-Manero G, Chien KS, Montalban-Bravo G. Myelodysplastic syndromes: 2021 update on diagnosis, risk stratification and management. *Am J Hematol*. 2020;95(11):1399-1420. 2. Fenaux P, Platzbecker U, Ades L. How we manage adults with myelodysplastic syndrome. *Br J Haematol*. 2020;189(6):1016-1027. doi:10.1111/bjh.16206. 3. Platzbecker U, Kubasch AS, Homer-Bouthiette C, Prebet T. Current challenges and unmet medical needs in myelodysplastic syndromes. *Leukemia*. 2021;35(8):2182-2198. 4. The MDS Foundation. www.mds-foundation.org. Accessed August 3, 2023. 5. The MDS Alliance. www.mds-alliance.org. Accessed August 3, 2023. 6. Leukemia & Lymphoma Society. www.lls.org. Accessed August 3, 2023. 7. The Aplastic Anemia and MDS International Foundation. www.aamds.org. Accessed August 3, 2023. 8. American Cancer Society. www.cancer.org. Accessed August 3, 2023. 9. Patient Advocate Foundation. www.patientadvocate.org. Accessed August 3, 2023. 10. PAN Foundation. www.panfoundation.org. Accessed October 24, 2023. 11. Be the Match. www.bethematch.org. Accessed August 3, 2023. 12. National Bone Marrow Transplant Link. www.nbmtlink.org. Accessed August 3, 2023. 13. Blood & Marrow Transplant Information Network. www.bmtinfonet.org. Accessed August 3, 2023. 14. Cleaning for a Reason. www.cleaningforareason.org. Accessed August 3, 2023. 15. Road to Recovery. American Cancer Society. www.cancer.org/support-programs-and-services/road-to-recovery.html. Accessed August 3, 2023.

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Choosing a treatment with my healthcare provider

- ▶ Ask your healthcare provider:
 - What are the **treatment options** available to me?
 - What do you consider to be the **best treatment** for me, and **why**?

My MDS Treatment Plan

- ▶ The treatment my healthcare provider and I have decided is best for me is:

Key questions to ask my care team:

- What **signs** and/or **symptoms** should I **immediately report** to my care team?
- What **signs** and/or **symptoms** should alert me to **call 911** and/or **go to the emergency room**?
- Is my treatment taken **by mouth** or does it require an **infusion**?
- How **often** will I need my **treatment**?
- What are the **side effects** of my **treatment** and what should I expect?
- What possible **late- and/or long-term effects** might I experience from **treatment**?
- How **often** will I need to follow up with my **healthcare provider**?
- When should I see **improvements** in my **symptoms**?
- Will I need a **caregiver** to receive this **treatment**?
- How much will my treatment **cost**?
- What **financial resources** are available?
- How does my diagnosis of MDS **impact me**?
- How **often** will I need **blood work/lab tests**?
- Will I be able to **continue work** and **complete activities of daily living**?
- What will my **quality of life** be?
- How will this **impact my family**?
- What **services** are available to help with **coordinating my care** (for example, assistance for transportation needs)?
- What additional **patient/caregiver support** is available?

My Care Team Contact Information: